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ABSTRACT

Long-term care workers (those who are paid to provide custodial care for long-term patients in nursing homes or at home) must care for a growing number of increasingly disabled or dependent persons. They are working for agencies and institutions under growing pressure to increase productivity. They face new training and competency requirements, and most work for low wages and few benefits, a situation that is unlikely to change soon. This crisis is real and will only get worse. The burdens of cost containment cannot be borne largely by an exploited female work force. As comprehensive long-term care programs are debated, questions of financing and reimbursement are not the only issues. Service delivery is a central issue. Who will provide daily care? How will providers be recruited, trained, and retained? The solutions will require a new model of care. Nursing aides and home health aides are oppressed by the acute medical model that still dominates long-term care services, as "skilled" and "custodial" categories of care created by Medicare lock them into underclass status. Are these workers truly "unskilled," is the real issue the disdain in which caregiving and nurturing is held? Since the general perception is that anyone can do it, and those who do are nearly all women, the work is not truly valued. Long-term care workers and their advocates are responding to these pressures by organizing to ensure both the quality of long-term care and the quality of worklife for paid long-term care workers. (Includes 37 reference notes.) (KC)

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GRAY PAPER

THE WOMANLY WORLD OF LONG TERM CARE: THE PLIGHT OF THE LONG TERM CARE WORKER

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OLDER WOMEN'S LEAGUE

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- TILL DEATH DO US PART: Caregivers of Disabled Husbands (revised 1986)
- DEATH AND DYING: Staying in Control to the End of Our Lives (1986)
- HEALTH CARE FINANCING AND MIDLIFE WOMEN: A Sick System (1986) (Insert on Medicare Catastrophic Coverage Act)

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THE WOMANLY WORLD OF LONG TERM CARE: THE PLIGHT OF THE LONG TERM CARE WORKER¹

I. INTRODUCTION

Long term care, recently the hot topic among policymakers and on Capitol Hill, is nothing new to women. Women, because of their longevity, constitute 74% of the nursing home population.² Women, because of their "nurturing" role, serve as 75% percent of unpaid caregivers in the home.³ And women, because of their low status in the paid labor market, are over 90% of the *paid* attendants, both in the home and in nursing homes.⁴

In this womanly world a crisis is building—a crisis fueled by four immutable developments:

- 1) Increased longevity;
- 2) Increasing numbers of older Americans;
- 3) Increasing opportunities for women in the paid labor market; and
- 4) Fewer children per couple available to assist.

Long term care is one of the most critical aging policy issues facing the United States as a whole. According to a recent poll, nearly half of all Americans have faced the long term care issue in their own families and another 20 percent expect to face the issue within five years.

Most older persons in need of assistance are not in nursing homes, but live at home, and are assisted by seven million unpaid family members, 75%—or over five million—of whom are women.⁵ Day after day, they help bathe, feed, dress, and toilet family members unable to do these "activities of daily living" (ADLs) independently. They change the sheets, clean house, prepare meals, do laundry and all the other daily tasks that make it possible for the relative to remain in the community. They make sure medicine is taken, give enemas, change dressings, and monitor health problems.

¹ This Gray Paper was adapted from *Chronic Care Workers: Crisis Among Paid Caregivers of the Elderly* (1988) by Alice Quinlan; a joint project of the Older Women's League and the American Federation of State, County and Municipal Employees, AFL-CIO. The section on the disability movement was added by the adapter, Frances Leonard, Esq., (1989).

² *Concerns of Older Women*, American Society on Aging, March 1988.

³ According to a recent study by the American Association of Retired People (hereinafter AARP) and the Travelers Companies Foundation (1988).

⁴ "Employed Persons by Detailed Occupation, Sex and Race," *Annual Averages, Employment and Earnings* vv 25-35 (January 1978-1988).

⁵ AARP, *op.cit.* Older Women's League, "Failing America's Caregivers: A Status Report on Women Who Care," (1989), p.1.

The assistance they give is not "free." Caregivers pay a high price—physical, emotional, and financial—for the services they provide. Fifty-five percent of all family caregivers work outside the home, and many care for their own children as well.⁶ Policymakers and service providers are beginning to recognize and address the needs of unpaid caregivers, through respite programs, caregiver support groups, adult day care, and information and referral programs.⁷

But little attention has been focused on *paid* attendants who provide the same daily services. In low-wage jobs giving care deemed "custodial," they are the backbone of the nursing home and home health care industry. These attendants, too, are overwhelmingly women. They do the same labor-intensive, demanding work as unpaid caregivers but they do it for (initially) strangers, not family members. They work in the same settings as health professionals, but with none of the recognition or status, and substantially fewer benefits and lower wages.

The focus of this Gray Paper is on long term care workers: persons who are paid to assist those who need it, most of whom are elderly. They are health-care service workers in long term care settings—in nursing homes and related facilities, and in private homes.

Their job titles vary. In nursing homes, where they provide up to 90% of patient care, they are nursing aides.⁸ In private homes, they may be called by scores of different titles. "Home health aide" is used here. Although there are very distinct differences in working conditions between those who provide assistance in the home and those who work in nursing homes, their role and status as long term care workers justify a joint examination.

At a time when the need for chronic care services is increasing, there is a growing shortage of adequately trained nursing aides and home health care workers. This shortage can be directly linked to the woefully inadequate pay and fringe benefits offered these long term care workers and to the adverse working conditions including hours of work, understaffing, lack of training and absence of promotional opportunity.

It is long term care workers and not doctors and nurses who provide most of the

⁶ AARP, *op. cit.*

⁷ Stone, R., Cafferata, G.L., and Sangl, J., "Caregivers of the Frail Elderly: a National Profile," (National Center for Health Services Research (1986)); House Select Committee on the Aging, "Exploding the Myths: Caregiving in America," (1987); Sommers, T. and Shields, L., *Women Take Care: The Consequences of Caregiving in Today's Society* (1987); Coleman, V., *Til Death Do Us Part*, an OWL Gray Paper (1986).

⁸ Institute of Medicine, *Improving the Quality of Care in Nursing Homes* (National Academy Press, 1986; U.S. Senate Committee on Aging, "The Long-Term Care Challenge," *Developments in Aging*: 1987, v. 3 (1988), and "Home Care at the Crossroads," (April 1988); Rivlin, A. and Weiner, J. *Caring for the Disabled Elderly: Who Will Pay?* (Brookings Institution, Washington, DC 1988).

long term care, yet during public debate on health care policy they are often ignored as a key element to ensure success in providing an adequate supply of quality care. Therefore, it is in the interest of both long term care workers and those who require their services that the workers who feed, bathe, and dress elderly and disabled individuals receive adequate pay and benefits.

II. NURSING AIDES

There are over 25,000 nursing and related care homes (such as board and care) in the United States, with a total of over 1.7 million beds.⁹ Almost 90% of these beds are in nursing homes, which employ nearly one million individuals in a capacity of "nursing aide, orderly, or attendant."¹⁰

The total number of residents—as distinct from beds—in these facilities was 1,553,000 in 1986; persons over age 65 accounted for 90% of those residing in nursing homes.¹¹

Nursing aides are overwhelmingly women (90%) and very disproportionately African American (31%).¹² In contrast, in 1987 the labor force as a whole was 45% female and 10% African American. During the past ten years, the number and proportion of women, African American and Hispanics who work as nursing aides has grown steadily.¹³ Recent immigrants also contribute to the nursing aide pool; for example, around San Francisco the Filipino community is heavily represented in these jobs.

Outside metropolitan areas, wages are lower, often hovering around the minimum wage. In general, hourly wages were higher in cities where a greater proportion of workers were union members and/or where a greater proportion of part-time aides worked.¹⁴

Medicaid reimbursement policies are also a strong determinant of nursing home worker wages. Medicaid pays for almost half the total cost of nursing home care in the U.S., and reimbursement rates vary from state to state. Because labor

⁹ National Center for Health Statistics, Sirocco, A., "Nursing and Related Care Homes as Reported from the 1986 Inventory of Long-term Care Places," *Advance Data from Vital and Health Statistics* No. 147, Jan. 22, 1988 (Public Health Service, Hyattsville, MD). These figures do not include 734 hospital-based facilities, nor do they include facilities primarily for the mentally retarded.

¹⁰ Bureau of Labor Statistics, *National Industry-Occupational Matrix, 1986-2000* (Dep't of Labor, 1986) at 524.

¹¹ *Chronic Care Workers: Crisis Among Paid Caregivers of the Elderly*, *op.cit.*

¹² "Employed Persons by Detailed Occupation, Sex and Race," *op.cit.*

¹³ *Ibid.*

¹⁴ Bureau of Labor Statistics (hereinafter BLS), *Industry Wage Survey: Nursing and Personal Care Facilities, September 1985*, BLS Bulletin 2275, March 1987 (Dep't of Labor, Wash. DC).

costs are 75% of total costs, wages are closely linked to these figures.

In a study of wages in female-dominated and male-dominated occupations, the Census Bureau found that nursing aides averaged \$3.98/hour in 1979, and only \$3.91/hour (in 1979 dollars) by 1986. In general, they found that working in an occupation with a high proportion of women has a negative effect on earnings.¹⁵

Finally, a very significant portion of nursing aides earn less than the average. Thousands earn the minimum wage, which by 1987 meant that the full-time aide working at minimum wage and her family had fallen to 80% of the poverty level.¹⁶

III. HOME HEALTH AIDES

Home health agencies provide or broker services ranging from high technology medical care—such as home dialysis, chemotherapy, and tube feeding—to personal daily care, food preparation, and other household assistance that enable many people to live at home.

The home health care industry is complex and diverse, characterized by rapid recent growth, increased corporatization, uneven government regulation, and fragmented funding and service delivery mechanisms.

In 1988, there were between 11,000 and 12,000 home health agencies in the United States.¹⁷ Only about half of them have been certified for reimbursement under Medicare/Medicaid. The remainder are licensed and/or regulated in varying degrees by state governments in 35 states.¹⁸ Unlike the nursing home industry, where non-certified and unlicensed facilities serve only a small portion of the total number, about half of home health services are delivered by home health agencies that have not been certified under Medicare/Medicaid. Prior to 1980, most home health service providers were either government agencies or the traditional visiting nurse associations. But when legislation permitted the certification of for-profits regardless of state licensure, their numbers increased rapidly.

With little comprehensive data available on home health agencies, it is not surprising that information about their non-professional employees is sparse at best. But the reason is not only that the industry as a whole has experienced rapid growth, is unevenly regulated, and is fragmented among various agency bases and funding sources. The problem is also the lack of a single commonly

¹⁵ *Male-Female Differences in Work Experience, Occupation, and Earnings: 1984*, Current Population Reports, P-70, No. 10 (Census Bureau, 1987), Table 11.

¹⁶ Shapiro, I., *No Escape: The Minimum Wage and Poverty* (Center on Budget and Policy Priorities, 1987), p. 19.

¹⁷ U.S. Senate Committee on the Aging, "Home Care at the Crossroads," Special Committee on the Aging, (April 1988), p. 20; and Foundation for Hospice and Homecare, "Basic Home Care Statistics: The Industry 1988," p. 6.

¹⁸ *Ibid.*, "Home Care at the Crossroads."

accepted occupational title to name these long term care workers who work in the homes of individuals.

Scores of titles have been used to describe the work they do. Some examples include: chronic care worker, homemaker-home health aide, home care worker, homemaker, home health aide, personal care worker, home attendant, home helper, chore worker, family care worker, companion, home nursing assistant, independent provider/contractor, personal service assistant, and home help support worker.¹⁹

Confusion about job titles is also fostered by varied funding mechanisms. As one Visiting Nurse Association (VNA) director explained,

The home health aide of the Medicare program is essentially doing the same tasks as the homemaker of the Title XX programs, and the same tasks as the personal care aide of the Medicaid program, and the same tasks as the home aide in some programs for the aging.²⁰

Under whatever title, one researcher estimated that there were at least 300,000 home health aides in the United States.²¹

IV. GROWING CRISIS AMONG LONG TERM CARE WORKERS

Although there is a dearth of good statistical data on long term care workers, some studies have permitted a sketch of the typical individual who provides these services. For example, the majority of home health aides interviewed in one study in New York City were:

- √women (99%);
- √African-American (70%) and Hispanic (26%);
- √foreign-born (46%);
- √widowed, divorced, or never married (64%);
- √middle-aged (average age was 47);
- √not high school graduates (64%);

¹⁹ Many disability rights activists find the use of the term "care" in the worker's title offensive, because it is demeaning to the person using the assistance. "Personal service assistant" would be preferred by this group. We have used "long term care worker" in this paper because "long term care" is a term which is understood in the aging field, and because at a meeting of representatives from several disciplines on the problems of this group of workers (convened by O.W.L.), "long term care worker" was the preferred reference.

²⁰ Testimony of Hall, H., "Black Box of Home Care Quality," Hearing before the House Select Committee on Aging (July 29, 1986), p. 67.

²¹ Feldman, P., and Sapienza, A., "Comparison of Questionnaire Results Across Sites: Homemaker/Home Health Aide Survey," Unpublished Report (Harvard University School of Public Health, January 1987), pp. 2-3.

- √median family income \$8000;
- √primary support of family (74%);
- √had children living at home (65%);
- √without health coverage (32%) or with minimal coverage (68%);
- √having difficulty paying bills and making ends meet (85%).²²

The best data currently available confirms the image of long term care workers as midlife women, disproportionately minorities, who work for low wages and few benefits. In some parts of the country, a shortage of workers is growing, even as the need for services is increasing.

A) Recruitment and Retention

Given the low wages and benefits, it is not surprising that long term care workers change jobs often or leave the field entirely. Among nursing home workers, nursing aides have the highest turnover rates, ranging from 70% to 100% a year; it is not uncommon for half of the aides to leave their jobs within the first six months.²³ On average the turnover rate is 60% for "paraprofessionals" who work in home care; 80% to 90% leave within two years.²⁴

There are many reasons why long term care workers are difficult to recruit and retain. The most frequently cited include:

- √low wages, few benefits;
- √for home aides, unpredictable income due to sporadic hours;
- √inadequate training, orientation and supervision;
- √unpaid classroom training;
- √no upward mobility, few and small wage increases;
- √stressful working conditions;
- √no pay adjustments for difficult patients or families;
- √certain dangerous neighborhoods and substandard housing;
- √no reimbursement for uniforms;
- √no reimbursement for travel between and with patients;
- √treatment as "second class" employees; and
- √the availability of better jobs.²⁵

Training is cited as a problem by many: by long term care workers, who feel they are not adequately trained or are stressed because they must train others; by consumer advocates, who see training as a critical element in the provision of

²² Donovan, R., "The Health and Social Needs of Home Care Workers: Preliminary Report," in *Plight of the Home Care Worker: Report of the Manhattan Borough President's Hearing on April 29, 1987* (January 1988), pp. 97-113; and Lombardi, T., "Recruitment, Training and Retention of Home Care Workers: A serious Problem," Health Bulletin #88, New York State Senate Health Committee, Task Force Progress Report, Dec. 1, 1987). p. 205.

²³ Institute of Medicine, *op.cit.*

²⁴ "Home Health Aide Services for Medicare Patients," Office of the Inspector General (Dep't of Health and Human Services, April 1987), pp. 15-16; and Lombardi, *op. cit.*

²⁵ Chronic Care Workers, *op.cit.* p. 17.

quality care in nursing homes and at home; and by providers, who must constantly deal with recruitment, training and the costs associated with worker turnover.

Unfortunately for everyone, training is all too frequently a hit or miss operation. More than thirty states have *no* requirement for the number of hours of training required for nursing aides in nursing homes; the rest have requirements varying from 19 hours (Texas) to 150 hours (California).²⁶ As of 1986, only 13 of the 34 states with home health licensure laws had any stated requirements for the duration and content of home health aide training.²⁷ Studies of how training works in practice are illuminating. In a Texas study, the researcher found that most aides had *no* preparation for their work besides on-the-job training.²⁸ Many of the nursing aides reported that they began working the same day they were interviewed and that their orientation consisted of following another aide. This "buddy system" was the most commonly used method of orientation and created conflicts for experienced aides who felt that the responsibility to train other aides contributed to patient neglect.

B) Shortages of long term care workers

Throughout the country, acute and long-term health care providers have felt the impact of a shortage of registered nurses (RNs) that is critical in many places. Less attention has been directed to a similar shortage of long term care workers.

Long term care workers are in extremely short supply today in some areas, most notably in northeastern and in western states. But the experience of these geographical areas portends a shortage that will hit the entire country over the next 15 years.

One fact, little recognized by policymakers, is that the full-time family caregiver, now standing between the elder and the nursing home in millions of homes, is a disappearing breed. Few women today who are younger than 50 expect to spend a full lifetime working in the home. By the time an older relative needs assistance, the daughter (sister, wife) will be in the paid labor market, and not in a position to leave it. She will still be expected to take responsibility for the situation, whether that means hiring, firing, and supervising the worker, or coordinating the day care schedule with all the other pieces—but she will have to

²⁶ American Bar Association, "The Black Box of Home Care Quality," Report to the House Select Committee on Aging (August 1986), p. 29. Recent federal nursing home reform legislation requires a minimum of 75 hours of training for nursing aides in all states. States are now revising their requirements to meet the federal standards.

²⁷ Erdman, K., and Wolfe, S., *Poor Health Care or Poor Americans: A Ranking of State Medicaid Programs* (Public Citizen health Research Group, 1987) p. 81; and Burger, S., *State Nurse Aide Training Survey Results* (National Citizens' Coalition for Nursing Home Reform, December 15, 1987), pp. 26-27.

²⁸ Wagnild, G., "A Descriptive Study of Nurse's Aide Turnover in Long-Term Care Facilities," *Journal of Long-Term Care Administration* 16 (Spring 1988), pp. 21-22.

do this from her workplace. It will be she who takes her own sick leave and vacation days when plans fall through; it will be she who rushes home from work early, and arrives late. In addition to "latchkey kids" we will have "latchkey elders."

In addition, women under the age of 55 had fewer children than their older sisters. They parented the baby bust. Each couple, therefore, will have fewer candidates available to assist them in their later years, because there are fewer children to form the caregivers' pool.

And finally, increasing longevity will swell the ranks of the older population at the same time the baby boom swells its ranks by its sheer numbers. Our older population will be much larger, it will be older, and it will have fewer family members to assist it.

Thus the current reliance on unpaid caregiving in the home will fail beginning with the generation now approaching 70 (about 30 million Americans are over 65, and three million are over 85).²⁹ This group will need to rely heavily on paid long term care workers in the home, or nursing home, in numbers as yet unanticipated.

The Department of Labor (DOL) projects an increase of 425,000 *new* nursing aides by the year 2000.³⁰ More than 90% of these new aides will be needed in nursing homes. At the same time, aide employment in *hospitals* will drop by 60,000 over the next 15 years.³¹ Thus the occupation "nursing aide" is becoming a nursing home, as distinct from hospital, occupation.

The DOL projects that home health aide jobs will increase even more than nursing aide positions, rating it among the fastest growing occupations during the next 15 years. By the year 2000, DOL estimates 110,000 new home health aide jobs—a growth rate of 80%.³²

Already, the pinch is being felt. Recently, more than half of nursing homes in one study reported a severe (24%) or moderate (30%) shortage of nursing aides.³³ Another study found that half of responding home care providers have difficulty recruiting and retaining home health aides.³⁴

In the face of shortages, a few providers are trying varied approaches to recruit and keep staff, such as subsidizing transportation and childcare or developing career ladders enhanced with education benefits. Others are tapping participants in welfare-to-work training programs.

A task force on home health aide shortages in Massachusetts—one of the

²⁹ AARP, *op. cit.*

³⁰ BLS, *Nat'l Industry-Occupational Matrix, 1986-2000, op. cit.*, p. 524.

³¹ *Ibid.*; and *Projections 2000*, BLS Bulletin 2302 (March 1988), p. 51.

³² *Ibid.*, *Projections*, pp. 56-57.

³³ "Nursing Home Shortages," fact sheet (American Health Care Association, 1988).

³⁴ *Ibid.*, and interview with Jones, P., National Association for Home Care, May 1988.

hardest hit states—concluded that a “significant increase in the hourly rate” was needed to attract new workers. But legislation requiring increases in the minimum wage has been opposed by the nursing home industry trade association, unless states would be required to raise Medicaid daily nursing home rates accordingly.

Both nursing homes and home health agencies are turning to temporary agencies to supply them with workers. Accepted by the industry in the past for their “relatively minor and useful role,” these nursing pools are now seen as competitors that adversely affect the cost and quality of care. In some areas of the country, the rates the temp agencies charged for pool workers were double the wages and benefits that nursing homes paid to their regular staff. The nursing home industry now advocates the increased regulation of nursing pools and the rates they can charge.³⁵

C) Public Policy Changes

Key changes in public policy are also significant factors in the crisis among long term care workers. At the top of the list are the cost control efforts of the past five years and recently enacted legislation to promote quality in nursing home and home health care.

Cost Containment

The introduction of the prospective payment system under Medicare—in which hospitals are reimbursed by patient diagnosis rather than for services provided—has had a major impact on long term care workers. One immediate effect was to make it financially advantageous for hospitals to establish home care programs; there was a marked increase in such agencies after the institution of the prospective payment system.³⁶ Hospitals also had an incentive to discharge patients as soon as possible. Subsequently both nursing homes and home health agencies reported sicker, more disabled patients; at the same time, they faced increased denials of payment as a result of the federal agency's attempts to restrict eligibility.

States have also instituted cost-containment measures under Medicaid, which pays for almost half the total costs of nursing home care in the U.S. each year. By changing reimbursement formulas, states have cut payments and have greatly limited annual increases: 2% increases are common, and some providers have received no increases from year to year. With labor constituting nearly 75% of total costs, staffing levels and worker wages and benefits are hit hardest by these restrictions.

For long term care workers, the results have been increased workloads, low wage increases, pressure for greater productivity, and in the case of home care

³⁵ Ellet, V., “Providers Find Nursing Pools Formidable Competitors,” *Provider* (April 1988), pp. 43-44; and “Regulate Nurse Pools to Ensure Quality, Control Costs,” fact sheet (American Health Care Association, May 1988).

³⁶ Sankar, A., et. al., “Prospective Payment: Systemic Effects on the Provision of Community Care for the Elderly,” *Home Health Care Services Quarterly* 7 (Summer 1986), p. 105.

workers, the fallout from uncertainty over Medicare reimbursement.

Quality of Care

In 1987, Congress enacted nursing home reform legislation. One provision eliminates the distinction between skilled nursing facilities (SNFs) and intermediate care facilities (ICFs). An important difference between these designations concerned minimum staffing requirements. Skilled nursing facilities must have an RN Director of Nursing, one RN on the day shift and one licensed nurse (RN or LPN/LVN) on other shifts; intermediate care facilities must have an RN consultant 4 hrs/week, and one licensed nurse (RN or LPN/LVN) on the day shift. In 1986, fully half of the facilities certified by the federal government did not meet the SNF staffing standards.³⁷ As of October, 1990, all nursing homes participating in either Medicare or Medicaid must meet them.

Thousands of nursing homes will need to hire new licensed personnel at the very time when a growing shortage of nurses is creating intense competition for their services. First priority for improvements in wages and benefits is thus likely to be directed to RNs and LPNs over the next few years.

A second key provision establishes training standards for new nursing aides, who must have a minimum of 75 hours of training during the first four months of employment, after which they must be able to demonstrate competency.

As the training standard is implemented, it may benefit many aides through upgraded training that can support a career ladder, but screen out others who have difficulty with written tests or who need English language or basic literacy as a requisite for classroom training.

As originally enacted, Congress singled out nursing aides as the only group of nursing home employees to be listed in new state registries of persons who had abused or neglected patients. The registry has now been recast in positive terms as a listing of certified aides, and requires that all workers guilty of abuse or neglect be reported to the appropriate Board or registry.

V. THE DISABILITY RIGHTS COMMUNITY AND THE AGING

There is one group, of course, that has long addressed the problem of long term care workers, both in the home and in the institution. People with disabilities really came of age as a civil rights movement in the 1960's, when the Independent Living Movement was born on the campuses, as students with disabilities fought to dismantle the barriers which separated them from the American mainstream. These barriers were more than the physical ones of curbs, stairs, and restrooms. Attendant services were minimal because of cost, so the alternatives were limited to home care provided by relatives, or sheltered workshops, or institutions. When people with disabilities broke free of their reliance on others to advocate for them, worlds began to open up. Although not

³⁷ Mohler, M., "Improved Nurse Staffing: A Priority for the Safety and Quality of Care in U.S. Nursing Homes," Report of a Study Done for the U.S. Senate Special Committee on Aging, October 1987, p. 6 and Ex. D.

directly transferable in all particulars, much of the disabilities movement's experience with the development of personal attendant services can provide a model for the aging community.

A) Who Is In Control?

For example, the disabilities community has wrestled with the question of control. Traditionally, Medicare, Medicaid, or some other government payor would have to approve the need for assistance, and that assistance would have to be contracted for from a licensed or certified agency, such as the Visiting Nurse Association. Under this model, the personal assistant is hired, trained (if at all), supervised, fired, and paid by the service, not by the individual using the service. There is a world of difference between this system, and one which provides the money to the primary user who then procures and pays the personal services attendant him or herself. Although advanced age makes this amount of control impossible for some of the disabled elderly, for thousands, if not millions, control would make the difference between an active, involved old age, and one of dependency and powerlessness.

B) Job Quality for Long Term Care Workers

In addition, the disabilities community has confronted the issue of job quality for personal service attendants. Recognizing the inherent conflict between the reliance of the primary user on unrealistically low government reimbursement, and the entitlement of the attendant to a dignified job and a living wage, both interests have come together in the disabilities movement to jointly advocate for increased benefits, wages, training, and so forth.

C) The Medicalization Trap

The perils of medicalization of these services was obvious earlier to disabilities activists than aging advocates. If a medical professional, usually a physician, is the gatekeeper to the government funding, then control is in the hands of the medical profession rather than in the hands of the primary user him or herself. For example, if a service (say, adult day care) is funded through Medicare or Medicaid, a physician's okay will be required before funding can begin. And before a physician will certify need, there will have to be a medical problem. Thus adult day care becomes adult day *health* care, with its attendant baggage of medical professionals and licenses, which may or may not be appropriate in a given situation. If the medical profession is the gatekeeper to all personal services for the elderly funded by government or private insurers, then individuals will have to distort their circumstances to fit the requirements. The medical problem balloons in its importance as the funding vehicle, and of course, the individual loses control over the decision to use the assistance of a personal attendant.³⁸

D) The Importance of Funding Mechanisms

Because of the dominance of Medicare in the lives of all Americans over 65, and

³⁸ The World Institute on Disability in Berkeley, CA has pioneered much of the work on these issues.

the equally dominant role of Medicaid in the lives of most who require long term care, the aging community has naturally looked to Medicare/Medicaid amendments when new services are identified as needed. The short-term benefits of this approach are obvious: the programs are familiar and in place, the administration of them has been developed, the providers are familiar with the system. It is easier to advocate that home assistance services be provided through the Medicare/Medicaid funding stream, then it is to convince Congress that a new social program should be defined and financed. But in the long run, the aging community may be painting itself into a corner—a corner which is bounded by federal programs which are *medically* oriented, and which give large amounts of control over individual lives to the medical community. When an individual needs assistance tying her shoes, because she can no longer bend over for whatever reason, this should be defined as a social, not medical, need—and funded accordingly. She should not have to have her doctor certify her need; she is able to assess her need herself. If political realities are such that a gatekeeper is inevitably part of the picture, then an assessment should be made as to who that person should be. In the illustration above, a social worker trained in geriatrics would probably be more suitable than an MD. Some long term care proposals debated by Congress have recognized this, and specified social workers as case managers.

VI. STRATEGIES FOR CHANGE

√ **Coalition Building.** An OWL-sponsored Long Term Care Worker Task Force is working on improving the worklife of long term care workers. The task force includes representatives from labor, academia, legal services, and advocacy organizations. In addition, the aging and disability movements can gain much from each other by closer association and understanding of both their common and differing perspectives. Women's organizations can be educated about the preponderance of women as family caregivers, long term care workers, and the advanced elderly users of services, and brought into the coalition. Likewise, health advocacy organizations are a natural ally, as well as health provider associations, such as organized nurses. A broad-based coalition of labor, health, women, aging, and the disabled would be a powerful tool for change.

√ **Legislation.** Workers' needs should be addressed in all bills with a long term care component, and all bills addressing nursing home reform. It is imperative that all long term care provisions be scrutinized for technical and practical flaws, and by representatives from a variety of interest groups. In addition, state model legislation should be developed addressing medicaid reimbursements, licensing, pay scales, worker training, fair employment practices and the myriad of issues appropriate to state and even local legislation.

√ **Education.** Press conferences, media alerts, workshops, written materials—all do their part in educating the public to the need. OWL chapters can build meeting programs around the issues discussed in this Gray Paper, as well as hold workshops for the general public.

√ **Research.** OWL will develop a research agenda with the assistance of other interested organizations and members of the Long Term Care Workers Task Force. It will serve to call attention to the issues needing research. It is a fertile

field for research either on an academic level, or empirical grassroots research. Research is needed into pay equity, demographics, worker morbidity, and immigrant workers' needs. In addition, data collection is needed on the home health industry, especially noncertified groups.

VII. CONCLUSION

Without affordable access to quality long term care, millions of American families will continue to face severe hardship when confronting the need for such care—the grandparent with a broken hip or Alzheimer's disease; the spouse who suffers a stroke; the worker in the prime of life disabled by an accident; the child with cerebral palsy.

Long term care workers must care for a growing number of increasingly disabled or dependent persons. They are working for agencies and institutions under growing pressure to increase productivity. They face new training and competency requirements. And most work for low wages and few benefits, which is unlikely to change soon.

Those are the elements of the crisis, which is real and will only get worse. The burdens of cost containment cannot be borne largely by an exploited female workforce. As comprehensive long term care programs are debated, questions of financing and reimbursement are not the only issues. Service delivery is a central issue: who will provide daily care? And how will they be recruited, trained, retained? The solution will require the development of a new model of care.

Nursing aides and home health aides are oppressed by the acute medical model that still dominates long-term care services, as the "skilled" and "custodial" categories of care spawned by Medicare lock them into underclass status.

What constitutes "skilled" care? In what sense are nursing aides and home health aides *not* skilled workers? Are they workers without skills?

Long term care workers aren't the only ones who ask these questions. An RN cites the nursing home patient who observed, "if you stick a feeding tube down someone's nose, that's skilled care; if you feed him and plead with him and coax him to eat, which takes ten times as long, that's not skilled."

Or is the real issue the disdain in which caregiving and nurturing is held? Since "anyone can do it" is the general perception, and those who do are nearly all women, the work is not truly valued. In contemporary American society, that means it is not valued economically; low compensation is the norm.

Long term care workers and their advocates are responding to these pressures by organizing—through union activities, research, public education, and community projects—to insure both the quality of long term care and the quality of worklife for paid long term care workers.